

# BETTER COLLABORATION IN ORGANIZED RESEARCH:

**A Toolkit for Community Based Organizations and Researchers**

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New Jersey Minority Aging Collaborative



# RUTGERS



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- Trenton Health Team
- Other Community Based Organizations (CBOs) who participated in interviews, surveys, and focus groups

## INTRODUCTION

This document has been produced to give researchers and CBOs partnering in organized research the tools to work well together to do community research. The content was developed through a process of speaking to CBOs directly, hearing their recommendations and concerns, and providing background on basic terms, questions, and timelines of organized research.

While the toolkit is not exhaustive and many of its readers may have much more to add, it is the hope of its developers that this can be a pathway to better partnerships between CBOs and researchers as they jointly seek to do good research that fairly and respectfully engages with the community.

This document has been developed as part of the New Jersey Minority Aging Collaborative (NJMAC) of Rutgers University working within the “R24-Examining Diversity, Recruitment and Retention in Aging Research” Grant sponsored by the National Institutes of Health.

## COMMON DEFINITIONS OF RESEARCH

- A formal controlled process to answer something you don't know
- Systematic data collection conducted to potentially get answers
- Modeling of prediction models to see if data can be used accurately to test improvements



*Note: Not all research projects have the same structure and rules. To create this toolkit we assumed the guidelines that are in place for many organized research projects.*

## RESEARCH PROJECT ROLES

- **Sponsor** – the organization that's paying for the research. I.e. NIH, university, private foundation
- **Institutional Review Board (IRB)** – A committee designed to review and monitor research for ethics
- **Principal Investigator (PI)** – The person responsible for the research and overall project (Generally is a university professor). They work for the university and cannot work on another organization's behalf.
- **Study Staff**
  - **Project Coordinator or Research Associate** – The person or persons who conduct the research and data collection and evaluate the project protocol
  - **Research Assistant** – The person or persons who conduct daily project tasks such as data collection and general clerical work
- **Research Participant** – A person who voluntarily participates in research to provide data to the study
- **Other Partners** - CBOs, Consultants, Contractors,
- Fee-for-service



## TIMELINE OF RESEARCH

Typically, a research project spans 5 years. That includes the initial genesis of the idea through the reporting of results. An example of the 2 years between the finalization of an idea and the conducting of the research is displayed below:



***Depending on when CBOs are engaged in the process, certain elements are difficult to alter.***

## TOP 5 SUGGESTIONS FOR COLLABORATIVE ORGANIZED RESEARCH PROJECTS

1

**Relationship Building:** Build a bi-directional relationship with the people you are studying that is based on trust and respect

2

**Community Benefits:** Share how the community served by the CBO can be improved by the process or outcomes of the research

3

**Look like the Community:** People that look like or are a part of the community being studied are more likely to be well received

4

**Non-Extractive:** Ensure research tactics are non-extractive and leave communities in a better place without doing any harm

5

**Tap Trusted Sources:** Rely on those who already have trusted relationships with the community



## TOP 5 COMMON ISSUES TO CONSIDER IN COLLABORATIVE ORGANIZED RESEARCH

- 1** **No Translation:** Certain topics do not "translate" into other cultures, languages, and settings
- 2** **Poor communication:** Researchers use the ineffective ways of communicating that ignores the culture of a group and relies on jargon that is not well understood
- 3** **Rigid:** Researchers and/or CBOs are not open to hearing real feedback that might change their methodology
- 4** **Partnership Timeline:** CBOs and the community are not considered to be partners in both the design of the research and in examining its results
- 5** **Jumping in:** Researchers come with good intentions, but may lack the patience to fully understand and engage with the community

*How will you address this with your partners?*

## FOR RESEARCHERS

### ANSWERS RESEARCHERS SHOULD PREPARE PRIOR TO APPROACHING A CBO TO PARTICIPATE IN A RESEARCH PROJECT

- How will the study benefit the community in the short-term and in the long-term?
- How will results be shared back to the community?
- How will the research acknowledge the history of systemic racism?
- How will the CBO be compensated?
- Will compensation really cover the CBO's costs?
- How will people be asked to participate?
- What project design and/or materials can a CBO provide input on? *I.e. Can a CBO review a flyer before it goes to the IRB?*
- Is there a plan for providing accurate translation of materials?



## WHAT COSTS ARE TYPICALLY ALLOWED ON A RESEARCH GRANT?

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### ALLOWED

- ✓ Fixed-rate participant-compensation
  - ✓ Pre-Approved Supplies and equipment
  - ✓ Salaries & Travel for University employees
  - ✓ Consultant fee (for defined consultant work)
  - ✓ Subawards/contracts
- 

### NOT ALLOWED

- ✗ Travel for non-university employees
- ✗ Salary for independent contractors not through a subaward/subcontract
- ✗ Rent for community office space
- ✗ Training for community organization staff
- ✗ General operating or improvement costs for universities or CBOs
- ✗ Research costs not related to the funded proposal
- ✗ Costs not permitted by local, state or federal laws
- ✗ Petty Cash/ Gifts

## ESSENTIAL RESOURCES FOR CBOS TO HAVE IN PLACE BEFORE DOING RESEARCH

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- Executive buy-in and organizational support of the project
- Budget to be able to cover costs so folks can work
- Relationship with the community
- Understanding of research processes (what you are being asked to do)
- Staff capacity to do the work

## POSSIBLE WAYS TO SHARE RESULTS

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- Aggregated results can be published or discussed
- Results that directly impact participant safety will be relayed directly to the participants according to ethical principles and law/regulations. For confidentiality reasons, these are generally not shared with CBOs.
- Individual results may or may not be returned to participants. Each study is different.
- De-identified data, tables, and graphs cannot be shared publicly until formal presentation or publication of results

## QUESTIONS A CBO SHOULD ASK ITSELF BEFORE AGREEING TO PARTICIPATE IN A RESEARCH PROJECT

- Who owns the information and how will it be used?
- What are the financial burdens we are being asked to take on?
- Can we request overhead costs or charges?
- What resources are being provided? What do we have to do on our own?
- How long is the total engagement with us?
- How can we work to help the people who participate in the project?
- Do I understand the research method and strategy being used in this project?



# CHECKLIST FOR CBOS BEFORE ENTERING A RESEARCH COLLABORATION

## EXECUTIVE BUY-IN AND ORGANIZING SUPPORT OF THE PROJECT

*People capable of making, approving, and executing organizational decisions regarding research collaboration:*

\_\_\_\_\_ Support Y / N  
NAME ROLE

\_\_\_\_\_ Support Y / N  
NAME ROLE

\_\_\_\_\_ Support Y / N

*Staff responsible for the research partnership?*

Primary: \_\_\_\_\_  
NAME ROLE

Back-up: \_\_\_\_\_  
NAME ROLE

## BUDGET TO BE ABLE TO COVER COSTS TO SUPPORT THE WORK BEING DONE

\_\_\_\_\_ hours per week of CBO staff whose job duties fit with research role

\_\_\_\_\_ hours per week of CBO staff whose job duties can be modified

\_\_\_\_\_ hours per week of new hire needed

\$ \_\_\_\_\_ for materials, etc.

# CHECKLIST FOR CBOS BEFORE ENTERING A RESEARCH COLLABORATION

## STAFF CAPACITY TO DO THE WORK & IMPORTANT RESOURCES TO REQUEST FROM RESEARCHERS

What are your organization's roles in this research collaboration?

1

**Host: Hosting researchers to conduct research activities on property you own, lease, or share:**

Expected of Researcher

CBO Can Take On

2

**Ambassador: Introducing researchers to your constituents so they can conduct research:**

Expected of Researcher

CBO Can Take On

3

**Facilitator: Promoting research to your constituents**

Expected of Researcher

CBO Can Take On

# CHECKLIST FOR CBOS BEFORE ENTERING A RESEARCH COLLABORATION

## STAFF CAPACITY TO DO THE WORK & IMPORTANT RESOURCES TO REQUEST FROM RESEARCHERS

What are your organization's roles in this research collaboration?

4

**Recruiter: Committing to recruit a certain number of participants into research activities**

Expected of Researcher

CBO Can Take On

5

**Advocate/guardian: Ensuring respect, equity, and safety of your constituents who participate in research**

Expected of Researcher

CBO Can Take On

6

**Consultant: Providing feedback on research design, conduct, and dissemination**

Expected of Researcher

CBO Can Take On



# CHECKLIST FOR CBOS BEFORE ENTERING A RESEARCH COLLABORATION

## UNDERSTANDING OF RESEARCH PROCESSES

Does your organization already host regular events during which researchers can present or engage your constituents?

YES    NO

Does your organization conduct its own review of research protocol (I.e., through an Institutional Review Board or a Research Committee)?    YES    NO

If yes, what is the typical approval timeline?

\_\_\_\_\_

Staff within your organization who has some familiarity with research who will review the consent form:

Primary \_\_\_\_\_ (name)

Back-up \_\_\_\_\_ (name)

Key Research Contacts

PI \_\_\_\_\_ (name)

Email/phone \_\_\_\_\_

Main staff contact \_\_\_\_\_ (name)

Email/phone \_\_\_\_\_

IRB email/phone \_\_\_\_\_

## NOTES

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